

**117<sup>TH</sup> MEETING OF THE NATIONAL CANCER ADVISORY BOARD (NCAB)  
MEETING OF THE SUBCOMMITTEE ON COMMUNICATIONS**

February 12, 2001  
7:00 p.m. – 8:30 p.m.

**Welcome/Opening Comments—Dr. Susan Love**

Dr. Susan Love chaired the meeting of the Ad Hoc Subcommittee on Communications with Dr. Susan Sieber serving as Executive Secretary. Dr. Love welcomed the subcommittee members and attendees and briefly reviewed the agenda.

**Office of Communications Update—Dr. Susan Sieber**

Dr. Sieber reviewed the updated organizational chart for the Office of Communications (OC). She described the five major programs comprising the OC, introduced the head of each, and briefly highlighted an ongoing project for each.

- Technology and Services—Mr. Michael Moore is the Associate Director for this program, which is composed of two branches: the Communications Technologies Branch and the Communications Services Branch. A major project recently approved is the development of an NCI Communications Technology and Research Center, which will include usability laboratories with testing, observation, and control rooms; training and design rooms which will be PC equipped and integrated with testing areas; and a technology evaluation facility which will investigate new computer equipment including hand-held devices.
- Media and Public Communications—An offer has been made to a candidate Associate Director for this group, pending lifting of the DHHS hiring freeze. This group houses the CIS and also the NCI press office; it is currently planning a science writer's seminar series that will be open to local and national media.
- Outreach and Partnerships—Ms. Elisabeth Handley is the Associate Director for this program, which works with organizational entities outside of NCI and also is responsible for NCI's various national information campaigns in areas such as I<sup>131</sup>, DES, Five-a-Day, and breast and cervical screening.
- Communications Coordination—Ms. Nelvis Castro is the Associate Director for this program, which, among other things, is leading NCI's branding campaign.
- Cancer Information Products and Systems—Dr. Anne Thurn is the Associate Director for this group, which is focused on maintaining and refining the NCI Web site and its major databases. They are currently piloting an Instant Messaging (IM) system that will allow the public to get real-time on-line assistance with PDQ and other services.

Dr. Sieber reported that she is close to selecting a deputy director for the OC as well.

## **Clinical Trials Education Programs in NCI's Office of Education and Special Initiatives—Charmaine Cummings and Margo Michaels**

Ms. Cummings described the Office of Education and Special Initiatives' (OESI) mission, which includes developing and implementing programs over the entire cancer continuum and increasing understanding of access to clinical trials. OESI's target audiences include: health professionals; patients and their families; patient advocate groups; and the public.

Ms. Michaels described the Office's efforts at developing five new documents on clinical trials. Each document is targeted to a different audience. The five documents are:

Clinical Trials Primer—Basic Edition. This document is a self-modulated interactive workbook on "everything you wanted to know about clinical trials." The target audience for this is advocates, survivors, and less familiar health care professionals.

Clinical Trial Outreach Kit. This is an interactive guide for individuals/organizations to develop specific clinical trial outreach activities within their organization and their community. It is designed for use with the basic edition of the primer and is targeted to advocates and educators.

Clinical Trials Primer—Professional Edition. This self-modulated interactive workbook is under development. When completed it will offer CME credit for health care professionals who seek a more "in-depth" understanding of clinical trials.

Clinical Trials Information for Research Teams. This self-modulated interactive workbook is still in development. When completed it will offer CME credit for professionals already involved in clinical trials and will feature in-depth information about clinical trial protocol development, recruitment, and patient protection.

Generic Trainer's Guide. This guide on how to run educational sessions in the community is still in development. It is designed for use with the entire series or any other cancer education program. It is targeted to anyone who wants to run cancer educational programs within their organization or community.

### **Board's Role in Promoting Clinical Trials vis-à-vis Medicare National Coverage Decision**

In Ellen Stovall's absence, Ms. Andrea Denicoff led a general discussion on the Executive Memorandum from President Clinton regarding the HCFA National Coverage Decision for Clinical Trials. Ms. Denicoff distributed a fact sheet outlining some of the most important aspects of the Memorandum. The Memorandum directs:

- the Medicare program to revise its payment policy to explicitly reimburse providers for the cost of routine patient care associated with participation in clinical trials

- HHS to take action to promote the participation of Medicare beneficiaries in clinical trials for all diseases
- HHS to launch an effort to educate beneficiaries and providers about this policy change
- NIH to evaluate the feasibility and advisability of taking additional action to increase the participation of seniors in clinical trials to ensure that researchers can determine the best therapies for older as well as for younger patients
- HHS to review the feasibility and advisability of using information contained in current NIH and FDA clinical trial registries to develop a national registry of all clinical trials receiving Medicare reimbursement.

Ms. Denicoff noted that interested persons can go to the HCFA Web site and get updates. She mentioned that meetings have taken place between NCI and HCFA staff to figure out the best way to publicize the new coverage decision. OESI is currently focusing on getting the information out to NCI-sponsored investigators. Staffs from both HCFA and CIS are being trained to answer questions related to the Memorandum.

Several subcommittee members indicated how important it is for both patients and practitioners to understand what is and what is not covered under the new decision. It was suggested that the document be widely disseminated through a variety of channels to ensure widespread awareness on this issue. The Subcommittee indicated that it would like to revisit the general issue at a future meeting.

#### **NCI's New CARRA (Consumer Advocates in Research and Related Activities) Program—Dr. Yvonne Andejaski**

Dr. Andejaski described how the CARRA Program was initiated. First, a process for assessing the state of involvement of advocates was developed. Advocate involvement at NCI was assessed through a workshop with consumer advocates and by interviewing NCI staff and advocates on their experiences at NCI.

Dr. Andejaski described some of the findings that emerged from the assessment. Advocates are selected based on diversity (usually of cancer type) and based on their personal contact with NCI staff. An advocate's role is rarely defined and orientations are provided infrequently. NCI staff indicated that advocates are included because they improve the programs. Advocates can assist with issues such as accrual, IRB review, and diversity. Often, advocates focus the agenda, set priorities, develop consensus, and question the status quo. Advocates are often the best advocates for science and scientists and they disseminate information to the public about cancer research. NCI staff said that they often do not include advocates because they are hard to find, for reasons of confidentiality and conflict of interest, it takes too much time, or they forgot. Some NCI staff also noted that the science is too complex for advocates and they are irrelevant to the topic. Also, NCI staff were concerned that advocates would be activists and inflexible.

Dr. Andejeski then described the CARRA Program. The guiding principles are to involve NCI and advocates, reflect the needs of all, define roles clearly, depict the Institute as a National organization accountable to the public, and one that is fair, open and impartial. The CARRA Program will also be attentive to issues of diversity and will routinely evaluate and modify procedures. The goal of CARRA is to give advocates the opportunity to work with NCI and foster an organizational atmosphere that values the contributions and perspectives of consumer advocates. The components of the CARRA Program will include recruitment, application, screening, selection of membership, support/consultation, orientation (advocates and staff), and evaluation/feedback. The CARRA Program will select about 150 people for service. Persons selected for the CARRA Program will be asked to participate in a variety of activities, both on campus and from their own homes. A modular orientation for CARRA Program participants will be constructed and made available on the Web.

To qualify as a CARRA Program participant, one must fill out an application that describes which constituency/group he/she represents, what their interest in science is (and describe how they are teaching themselves), any prior experience, the focus of their advocacy (disease specific or general) and their group experience. The application is more of a self-directed process advocates must follow as opposed to a form.

Subcommittee members were very excited to hear about the progress of this program and felt that it represents a wonderful opportunity to benefit both NCI and consumer advocates.

#### **New Business—Dr. Susan Sieber**

Dr. Sieber asked the Subcommittee members if they wanted to meet in conjunction with the next NCAB meeting. They responded in the affirmative but wished to have a lunch meeting instead of a Monday evening meeting. They decided that they would like to have each of the new OC Associate Directors put together a half-page handout with a biosketch and a description of what they plan to do so the Committee could get acquainted with the new staff of the OC. The half-page handout will be distributed prior to the next meeting. No formal presentations are planned for the next meeting; instead new OC initiatives will be discussed informally.

Dr. Susan Love  
Chair

Date

*Susan M. Sieber*  
Dr. Susan Sieber,  
Executive Secretary

17 Feb 2001  
Date